

April 21, 2021

Testimony:

- **FOR LD 1490, “An Act To Improve Home and Community-based Services for Adults with Intellectual Disabilities, Autism, Brain Injury and Other Related Conditions”**

Chairman Claxton, Chairwoman Meyer, Distinguished Members of the Joint Standing Committee on Health and Human Services:

My name is Alan Cobo-Lewis. I live in Orono. I have two 20-year-old sons, one of whom has a significant disability. That son is currently receiving children’s services and is undergoing transition to adult services.

LD 1490 is a policy bill to clarify the principles of the Home and Community Based Services (HCBS) waivers, improve their function, improve projection and reporting about any wait lists that develop or persist, and require the Department to fully disclose to the Legislature whatever resources may be needed to eliminate any projected wait lists. This is all information that you as legislators—and your successors—need to do your important job.

1 Wait List By Priority, Time on Wait Lists

In the 129th Legislature, after families on the Section 29 wait list cried out to the Legislature and the Executive for help, [the Department incorrectly reported to this Committee and to the Appropriations Committee](#) that there was no Section 29 wait list. It was only after being called out by families that the Department admitted the error began issuing quarterly updates on wait lists—but those updates have not actually come out quarterly, even before the pandemic. Secs 5-6 of LD 1490 would improve the frequency and quality of such critical reporting.

LD 1490 Sec 5 would require DHHS to report regularly on number of people in Priority 2 vs Priority 3 of the Section 21 wait list (something that DHHS regularly reported on years ago but which isn’t consistently in its current semi-regular reports), and LD 1490 Sec 6 would require DHHS to report regularly on how much time people spend on the various wait lists (something that DHHS has never reported regularly on). These are important elements in quantifying the human costs of the wait lists.

2 Amendments to Plan Required by Existing Statute

Existing statute at [34-B MRSA §5003-A](#) describes the “System of care for clients with intellectual disabilities or autism”, and existing statute at [34-B MRSA §5003-A\(3\)](#) already requires the Department to develop a plan for that system. Secs 7-11 would amend what needs to be in that plan:

2.1 Wait List Projections and Budget Implications

Sec 9 of LD 1490 would require the Department’s plan to project into the future what the wait lists would look like under current funding proposals, and Sec 10 of LD 1490 would require the Department’s plan to disclose what resources would be required to eliminate any wait lists that may be developing. While I respect the Governor’s role in proposing a budget, these features of LD 1490 are essential so that the Legislature can undertake its policy and funding decisions with the data it needs.

2.2 Participation in Waiver Design and Evaluation: “Nothing About Us Without Us”

Sec 8 of LD 1490 enshrines the principle of “[Nothing About Us Without Us](#)” by including waiver recipients—as well as direct service providers—in development of the Department’s plan, and Sec of 7 LD 1490 would require the plan to include quality metrics developed with input from those stakeholders. While the current

administration, to its credit, is including waiver recipients in its redesign plans, the requirement should be written into statute to ensure that it continues into future administrations.

3 Behavioral Add-On: Preventing Discrimination Against People with More Significant Needs

Sec 16 of LD 1490 would address an extant issue in waiver services: people with significant behavioral challenges are frequently denied access to community support because existing reimbursement rates may cover support needed by people with more modest needs but can't come close to covering support needed by people with more significant needs. Thus, people with more significant disabilities are effectively discriminated against. Sec 16 would address this by adding a "behavioral add-on" to the community support delivery structure to ensure that *all* people have access to the services and supports they need to be included in the community.

4 Principles of Service and Supports

Existing statute at [34-B MRSA §5610](#) codifies the fundamental values and guiding principles of service delivery to persons with intellectual disabilities and autism. Sec 14 of LD 1490 would add the principle that reimbursement rates so low as to interfere with service provision, extended stays on wait lists, and service definitions that exclude people with significant needs for support (as would be remedied by Sec 16, discussed above) are incompatible with the other fundamental values and guiding principles.

5 Tiered Reimbursement

Sec 15 of LD 1490 would require DHHS to adopt changes to Section 21 rules that they have already proposed for Section 29, for there to be a tiered reimbursement rate to incentivize community-based services over center-based services, and to incentivize individualized services over group services. As the Department has recently solicited public comment for such a change to Section 21, I thank them for that work, and I would leave it to the Committee whether to retain Sec 15 in any bill reported out.

6 Respectful Language

LD 1490 would also rename the "System of Care" in statute to "System of Services and Supports". This is proposed in order to be more in line with language about what people need to participate in all aspects of home and community life. If the Department were to articulate a truly compelling reason to retain the "System of Care" language, then the Legislature might retain it in existing statute. But otherwise, it would send an important philosophical message to update the language, as in LD 1490 as introduced.

7 Committee Authorized to Introduce Legislation

Sec 13 of LD 1490 would also authorize the Committee to introduce legislation to address any issues that may come to light, including issues that may come to light through the reporting required elsewhere in the bill.